

A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions

(PRISMS Practical systematic Review of Self-Management Support for long-term conditions): Final Report

Scientific summary

Background:

Despite intense interest in supporting good self-management amongst people with long term conditions (LTCs), it can be difficult for commissioners to identify what works. In addition, although there is a plethora of evidence concerning self-management for some LTCs, many lack a tradition of research explicitly on self-management and, consequently, some patient groups may be overlooked.

We have adopted the definition of self-management proposed by the US Institute of Medicine. “Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions.”

Aim:

To undertake a rapid, systematic overview of the evidence on self-management support in people with one or more exemplar LTCs in order to inform commissioners and healthcare providers about what works, for whom, and in what contexts.

Objectives:

Phase 1

To agree in discussion with an Expert Advisory Group:

- Characteristics of LTCs of relevance to self-management
- Components of self-management support interventions to inform a taxonomy
- The selection of exemplar LTCs for detailed investigation in Phase 2.

Phase 2

To undertake a rapid synthesis of the evidence around interventions for self-management support in each of the exemplar LTCs from:

- Published systematic reviews of randomised controlled trials (RCTs) (“quantitative meta-reviews”)
- Published syntheses of qualitative studies (“qualitative meta-reviews”).

To conduct an original systematic review (SR) of primary studies concerned with the implementation of self-management support interventions in populations with the exemplar LTCs (i.e. phase IV implementation trials).

To synthesise the resulting meta-reviews and SR in an overarching narrative synthesis, to determine what is known about the likely effectiveness of self management support interventions with respect to health service resource use, health outcomes (including quality of life (QoL), symptoms, biological markers of disease, and equity).

Phase 3

To organise a multidisciplinary workshop as a result of the work undertaken in Phases 1 and 2 in order to:

- discuss our findings, and
- help develop practical recommendations for health service commissioners.

To identify research gaps for future primary research or research synthesis.

Results:

Phase 1

Twenty-seven (32.5%) of 83 invitees attended the workshop, including healthcare managers, commissioners, policy makers, third sector representatives and healthcare professionals.

Following the workshop, informed by the on-going reviewing, we developed a layered description of self-management support interventions with the following dimensions:

1. Recipients: patients, carers, health care professionals, organisations;

2. Components: education, information about resources, specific action plans and/or rescue medication, equipment, safety netting, regular clinical review, training to communicate with health care professionals, training for activities of daily living, training in psychological strategies, training for practical self-management activities, social support, monitoring with feedback to the patient, practical support with adherence, lifestyle advice and support;
3. Modes of delivery:
4. Personnel delivering the support:

In addition these interventions may be generic, culturally-specific or tailored to individuals. (1 and 2 constitute our proposed taxonomy of self-management support components.)

The characteristics of LTCs which the workshop suggested would be most important when developing services to support self-management were:

- Potential of self-management to improve symptoms, and
- Impact of symptoms on lifestyle.

Several other characteristics were also identified.

The four “priority” exemplar LTCs identified were: stroke, T2DM, asthma and depression. The “additional” exemplar LTCS were: COPD, CKD, dementia, epilepsy, hypertension, inflammatory arthropathies, IBS, low back pain, progressive neurological disorders and T1DM.

Methods:

Phase 2

Data sources

Quantitative and qualitative meta-reviews

We searched MEDLINE, CINAHL, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effectiveness from January 1993 to June 2012, in addition, for the four priority LTCs we searched: EMBASE, PsychINFO, AMED, BNI, and ISI Proceedings. We hand searched: Systematic Reviews, Health Education and Behaviour, Health Education Research, Journal of Behavioural Medicine, and Patient Education and Counselling.

Implementation systematic review

We searched MEDLINE (1980 onwards), EMBASE (1974 onwards), CINAHL (1982 onwards), PsychINFO, AMED (1985 onwards), BNI, Database of Abstracts of Reviews of Effects and ISI Proceedings (Web of Science) all to August 2012. We also hand searched Patient Education and Counselling, Health Education and Behaviour and Health Education Research.

Our search strategy was: 'self-management support' AND a wide range of possible terms for each of the LTCs AND 'systematic review' terms. Self-management search terms included: 'confidence', 'self-efficacy', 'responsib*', 'autonom*', 'educat*', 'knowledge', '(peer or patient) ADJ1 (support or group)' and '(lifestyle or occupational) ADJ1 (intervention* or modification* or therapy)' and relevant MeSH terms. For the implementation review we combined these with implementation study terms, e.g. 'real world', 'routine clinical care', 'phase IV'. We also searched for unpublished and in-progress studies.

Study selection

We included studies of populations with one or more of the exemplar LTCs, including adults, children and all ethnicities. Due to time and resource constraints we only included English language publications.

For the quantitative meta-review we included systematic reviews of RCTs of multi-component interventions, excluding mono-component interventions apart from education, which focused on, or incorporated, strategies to support self-management (defined above). In the qualitative meta-review we included systematic reviews of qualitative studies that might inform strategies to support self-management. In the implementation SR we were interested in any phase IV implementation intervention (i.e. delivered as part of routine clinical service) which focused on, or incorporated, strategies to support self-management.

Outcomes of interest were: use of healthcare services, health outcomes (including biological markers of disease), symptoms, health behaviour, quality of life or self-efficacy. We examined a limited list of outcomes in the additional quantitative meta-reviews.

Following group training, one reviewer selected possible relevant studies from the searches. Full texts of all potentially eligible studies were retrieved and assessed by one reviewer. At both stages a second reviewer conducted a random 10% sample check.

We used the R-AMSTAR (Revised Assessment of Multiple Systematic Reviews) quality appraisal tool to assess the quality of all included quantitative SRs and adapted it to assess the included qualitative SRs. Quality assessment was undertaken by one reviewer, with a random 10% check conducted independently by a second. Data were extracted by one reviewer using piloted data extraction tables, 10% of the completed data extraction tables were checked by a second reviewer.

Synthesis

The meta-reviews

We treated the included SRs, their findings and conclusions, as our “raw data”, we did not examine the original publications of their included studies. Evidence was weighted by the quality of the included SRs and the size of the studies they included. We assessed overlap between the individual studies included in the systematic reviews. Synthesis was narrative, for each LTC first we synthesised the findings of the quantitative and qualitative meta-reviews separately, then combined them.

The implementation systematic review

Meta-analysis was not appropriate due to substantial heterogeneity amongst the included studies. We used the whole systems approach as a framework for our narrative analysis. This considers interventions from a multilevel perspective engaging patients, professionals and the organisation in a collaborative approach.

Overarching synthesis

Finally we synthesised all the material together. We used the components of self-management support identified in our taxonomy and the characteristics of LTCs to analyse our data and look for patterns.

Results:

Phase 2

We included 30 qualitative SRs, including 515 unique studies, 102 quantitative SRs, including 969 RCTs, and 61 studies in the implementation SR.

Key themes arising from the meta-reviews

1. Supporting self-management is inseparable from high quality care for people with LTCs

The key theme from all our meta-reviews and the implementation SR was that supporting self-management is inseparable from the high quality care of people with LTCs. Commissioners and providers of services for people with LTCs should consider how they can promote a culture of actively supporting self-management as a normal, expected aspect of the provision of care.

In our reviews self-management was not a substitute for professional care. Far from feeling abandoned and left to look after themselves, supported self-management empowered patients to access best care and support, though potentially (and paradoxically) reducing health care resource use, especially in asthma and COPD.

2. Supported self-management must be tailored to the individual, their culture and beliefs, and the time-point in the condition

A recurring theme from the meta-analyses was the importance of tailoring the self-management support to the individual and their condition. There was abundant evidence from the qualitative meta-reviews suggesting that individuals' existing health beliefs frame their understanding of their condition, and they will tailor medical regimes and self-management strategies to fit into their own lives and beliefs. Quantitative meta-reviews in both type 2 diabetes and asthma identified the benefits of providing culturally-specific interventions. The nature of the LTC also emerged as an important factor in determining the self-management priorities.

3. Communication

A common theme in most of the qualitative meta-reviews is the importance of enhancing communication between healthcare professionals and patients. Our qualitative meta-reviews concluded that an on-going collaborative/ communicative relationship was highly valued. A sense of 'not being listened to' ran throughout the qualitative reviews, with examples of mismatch between professionals' and patients' understanding and aims for self-management behaviours.

The inter-related components of self-management support

Many components of multi-component interventions were described and trialled in the SRs, but no one component stood out as more important than any other. The two most common components of self-management support interventions were education and psychological support.

Information and education

Education, provision of knowledge and information about the LTC, was a component of all the interventions included in the quantitative SRs. A variety of formats were used (groups, individual, lay-led, computerised, school/workplace) and it was not possible to differentiate the effectiveness of one mode compared to another. There was some evidence that interactive learning was more effective than passive education and in at least three conditions there was evidence that education provided in isolation was not effective.

Support with psychological impact of LTCs

Psychological support was mentioned as potentially helpful in the qualitative meta-reviews for virtually all the conditions, and the majority of self-management interventions included an element of psychological support. Overall there was variable evidence for the effectiveness of these components across the different conditions, with strong evidence in some conditions (low back pain, rheumatoid arthritis, type 1 diabetes (T1DM)) In some conditions, benefit was not sustained long-term (low back pain, rheumatoid arthritis).

Practical support for physical care

Coping with activities of daily living was a key challenge for people with disabling conditions and occupational and physiotherapists played an important role in enabling patients to self-manage and maintain as much independence as possible.

Social support

The need for social support was a major issue highlighted in the qualitative reviews of some conditions such as T2DM and stroke.

Health or social care professional level

It was not possible to identify a 'preferred professional' to deliver self-management support. Training to provide the self-management support for the healthcare professional/lay mentor was common to all the interventions though professional training as an isolated intervention was ineffective.

Organisational level Culture of the organisation

Organisational support is crucial. Without the active support of their healthcare organisation, our implementation review revealed professionals struggle to integrate self-management support into their routine clinical care. Promotion of effective self-management support requires a healthcare setting in which everyone believes that care should be based on shared-decision making, and patients need to be equipped with the skills, knowledge and support to self-manage (implementation review). The organisation is responsible for providing the means (both training, and time/material resources) to enable professionals to implement self-management support, regularly evaluating self-management process and clinical outcomes and providing on-going encouragement to maintain good practice.

LTC characteristic specific self-management components

- Action plans were associated with conditions in which there was significant variability or risk of (serious/ high cost) exacerbations. The evidence for asthma action plans is particularly strong and as an integral component of asthma self-management support reduces exacerbations, emergency department visits and hospitalisations. In COPD, action plans had no impact on hospitalisation except as part of a multi-faceted intervention.
- Therapy rehabilitation was a feature of self-management support for several of the disabling conditions. Although the term self-management was not used, key aspects of therapy rehabilitation addressed coping with disability and rehearsing activities of daily living. This was an effective strategy, at least in the short term, in several conditions (stroke, progressive neurological disease inflammatory arthropathies) though not in dementia, and only effective in low back pain as part of a complex psychosocial intervention.

- Self-monitoring and feedback: The only LTC reported as benefitting from this was hypertension – an asymptomatic condition.
- Intensive education may have a particular role in complex medical conditions (such as type 1 diabetes mellitus (T1DM), or home dialysis in severe chronic kidney disease (CKD)) when specific training can enable patients to self-manage clinical tasks

The other characteristics of LTCs identified at the initial workshop were not associated with any disease characteristic-specific self-management components

Implementing a whole systems approach to self-management support

The pivotal role of organisational support

The implementation systematic-review suggested that effective interventions were multi-faceted and multidisciplinary. Actively engaged patients, working in partnership with trained and motivated professionals within the context of an organisation which prioritised and actively supported self-management. Whilst all three components are important, the culture of the organisation underpins and enables integration of self-management principles into routine clinical care. As in the quantitative meta-reviews, a range of professionals led self-management initiatives and diverse modes of delivery, including telehealthcare, were employed.

The broader setting of high quality LTC care

Many interventions were introduced in the context of developing services generally to improve the care of people with LTCs. An included review specifically addressed the role of setting in the context of adherence to asthma treatment by comparing RCTs which had provided one or more components of the Chronic Care Model (CCM). The review concluded that the more CCM components included within interventions, the greater the effects on inhaled corticosteroid adherence. Several implementation studies implemented self-management support within national/local programmes of LTC care, with improved clinical outcomes.

Leadership and implementing LTC support

Several studies described strategies for achieving the necessary organisational change to implement effective self-management support. Key messages were the

need for strong clinical leadership and commitment at the highest level to ensure that a self-management support was prioritised, involving stakeholders to ensure that professionals are motivated and 'bought in' to the process of change, training to ensure all staff have appropriate skills, availability of resources to enable on-going delivery of self-management programmes, and regular oversight and evaluation to sustain the programme (implementation review: diabetes COPD, asthma)

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